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ABSTRACT

This paper examines the unmet service needs and problems of persons with disabilities in rural and remote regions of New South Wales (Australia). Data were collected through consultations with disabled persons, families, and service providers in Sydney and four rural areas; a literature review; compilation of an in-depth inventory of service resources and usage; and analysis of statistical data. Among the findings, major themes focused on: (1) great distances to be covered and generally limited public transportation infrastructure; (2) social isolation of disabled people and their families; (3) negative encounters between clients and service providers, the insensitivity of urban-based organizations to the needs of rural people, and lack of adequate support or recognition from organizations to their service providers; (4) need for consumer involvement and flexibility in service provision in order to tailor services to the individual and the environment; (5) need for greater coordination among service providers; (6) consumer preference for locally based services; (7) problems in recruitment and retention of professionals in rural areas; (8) need to raise the awareness of service providers and the community about disabilities and related issues; (9) difficulties in obtaining timely information on disabilities for both disabled persons and professionals; and (10) the special needs and interests of disabled persons who are doubly disadvantaged by being women, of non-English-speaking backgrounds, or of Aboriginal and Torres Strait Island backgrounds. Strategies are suggested to meet needs in each of these areas. Contains 29 references. (SV)

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NEEDS ANALYSIS OF PEOPLE WITH A DISABILITY LIVING IN REMOTE
AND RURAL AREAS OF NSW

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NEEDS ANALYSIS OF PEOPLE WITH A DISABILITY LIVING IN REMOTE AND RURAL AREAS OF NSW

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ABSTRACT

The aims of the project were to: locate people with disabilities living in remote and rural areas of NSW, to identify their needs with regard to service provision, and to develop innovative strategies which address unmet needs.

This paper provides an overview of the project. Those interested in obtaining further information are referred to the document entitled: "Across the Divide: Solutions Distance, Diversity and Disability". This document is published in two volumes. Volume I looks at general issues arising for people with disabilities living in remote and rural areas. Volume II focuses on issues arising for Aboriginal people with disabilities living in remote and rural areas.

To the researchers' knowledge this is the first time that information of this breadth has been used as the basis for making recommendations about services for people with disabilities in remote and rural areas of Australia. This methodology provided access to systematically-collected information which rarely has been available for decision makers. The project gathered and integrated information about service provision from a wide range of sources to draw a picture taken from many perspectives including those of people with disabilities, carers, families, service providers and representatives of peak disability organisations; analysis of statistics and usage rates; and collation of published literature and other information. The project produced a set of recommendations or action oriented strategies designed to improve service provision. Many of these strategies are resource neutral, some require funding. Some already may be on the agenda of government departments or disability organisations, others involve reconceptualisation and the implementation of different models of service provision from those used in urban environments. Many of the issues which are important for people with disabilities living in remote and rural areas are also relevant for people with disabilities in general (whether they live in urban, remote or rural locations) and people in general (with and without disability) living in remote and rural locations. Any attempt to isolate those issues specific to the target group would have produced an unrealistic picture of needs and issues. Thus, much of the material emanating from the project has implications which extend beyond the target group for this particular investigation.

PHILOSOPHICAL FRAMEWORK

The project was conducted within the following philosophical framework:

- 'Customer focus': people with disabilities are individuals and services must have an individual focus rather than stereotyping people and assuming that because they have a disability they have the same needs, interests and abilities.
- Services (both generic and disability-specific) should assist people with disabilities in achieving empowerment, independence, quality of life and access to facilities.
- People with disabilities should play an active and equal role in planning and implementation of services (on an individual level, as members of committees and as employees).
- Most people with disabilities are not ill or sick, therefore models of service provision and organisations which are responsible for providing services should focus on 'wellness' and well people.
- Regions and areas are different, and service provision must be flexible to take into account geographic, social and economic variation. In particular it is important to remember that remote and rural areas are not the same, although they do share some common features which distinguish them from urban environments.

METHODOLOGY

The following conclusions were derived from a data collection which was designed to take into account several perspectives:

- (a) Consultations with people with disabilities, families and service providers which were held in Sydney with peak and key organisations and through field trips to four selected areas of NSW. (Three field trips looked at issues arising for people with disabilities in remote and rural areas in general, while the fourth focused on issues for Aboriginal and Torres Strait Island people with disabilities) A large number of people with disabilities, service providers and peak disability groups were consulted during the research process. Their views, experiences and information about services in remote and rural areas provide an invaluable perspective.
- (b) A literature review which incorporated Australian and overseas material.
- (c) Compilation of an indepth resource and usage inventory which describes services throughout NSW and an indepth description of the service environment in one major rural and remote region of NSW.
- (d) Analysis of statistical and other information.

RESULTS

Living in a remote and rural area has many advantages. These include clean air, open spaces and (in many areas) a strong sense of community and mutual respect. However there can be disadvantages.

The overriding themes emerging from this project were that major issues to be addressed in regard to service provision relate to transport, distance, isolation, consumer involvement, the nature of service provision (flexibility, coordination, location and the nature of work for service providers), community and service provider education, and patterns of communication. These themes are summarised below:

Distance. Greater distances to be covered and generally limited public transport infrastructure require a flexible approach to be taken to improving services. The issue is not just a matter of distance, but also of limited infrastructure available to transport people at reasonable cost across both large and short distances and of high costs associated with using a car as the major form of transport. For example, most public transport in remote and rural areas (when it is available) is inaccessible for people who use a wheelchair or who have mobility restrictions. Only a few of the larger regional centres have wheelchair-accessible taxis. Problems associated with distance occur for people with disabilities, carers, service providers and agencies. These issues which arise for all people living outside major cities, are compounded for people with disabilities. Strategies emanating from the project suggest a model of service provision which is designed to suit the needs of people with disabilities in country environments and which addresses the higher costs associated with transport of individuals, goods and services.

"It is going to be difficult to access post-school training for my child if we can't arrange transport to get her to it." (Parent of a child with a disability)

Isolation. Isolation is an accepted part of the chosen lifestyle for most country people. It reflects not only geographic, but also social, cultural and family factors. The nature of remote and rural living is isolating in itself, however disability should not heighten isolation. Isolation and disability often contribute to feelings of loneliness and severely impinge on people's abilities to politicise the issues concerning them and to lobby decision makers. People with disabilities living in remote areas have limited opportunities to meet in groups and to join gatherings. Those in rural centres have more opportunity, but problems associated with physical access and transport often prevent such meetings. The infrastructure of many rural towns inhibits participation for people with disabilities. This results in segregation, hampered social development and continued entrenchment of the belief that people with and without disabilities are different. Distance from services raises many issues in regard to obtaining services, respite care,

support and access to facilities. Issues include overcoming the effects of isolation, providing assistance to families who act as carers and for providing services for Aboriginal people who live in isolated communities.

Service provision. This issue generated the widest range of comments during consultations and field trips. In many cases views were expressed with some forcefulness and emotion. It was clear that people with disabilities, families and carers could report many negative encounters with services. In addition, many service providers reported that they were working under difficult conditions and often felt that they did not obtain adequate support or recognition from their organisations. Many agencies and organisations had given very little thought to the appropriateness of their services within remote and rural areas. Some provided no services, expecting clients to come to Sydney. Other agencies were aware of deficits but had little idea of how to address them. Many organisations were not fully aware of the needs of people with disabilities living in remote and rural areas and had few statistics about their client populations or about the population diversity within their catchment areas. While organisations were aware that people with disabilities were experiencing problems, organisations were unable to indicate the extent of the problem or specific concerns of these clients. Issues concerning Aboriginal and NESB people with disabilities were largely undocumented and organisations had limited contact with these groups. However, organisations strongly believed that attention should be directed towards ensuring that these people were not excluded from service provision.

Consumer involvement. From consultations it became apparent that people with disabilities are frequently not consulted about the services provided for them. Many people believe this has resulted in wastage of resources and in services which are not tailored to the needs of residents of remote and rural areas. Flexibility. A major theme arising from the project is the need for flexibility in service provision. Services must be tailored to the individual and to the environment: strategies which may work in the city may not necessarily be effective in remote and rural areas. Many agencies have yet to recognise this.

Coordination. Greater coordination between services is required to achieve more effective use of resources, reduce duplication between services and reduce the number of gaps in service provision in remote and rural areas. Strategies are provided for enhancing coordination between services and between service providers.

"I've known people to fall between services and so are unable to access anything. For example, a man in my caseload with a mental illness is not eligible to access disability employment support services." (Service provider, Dubbo)

Location of services. Consumers expressed a clear preference for provision of services locally. For many reasons, local service provision is perceived as more effective and satisfactory for the client. These reasons include reducing disruption, distress and discomfort associated with travel and difficulty in obtaining regular access to services and to follow-up visits.

Service providers. The project revealed that it is difficult to attract professionals to work in the country and that turn-over rates are high. Many service providers stated they were working under very difficult conditions and that they did not obtain adequate support or recognition from their organisations. Coleman (1987) notes the need to develop career paths for rural workers and to develop networks between staff working in different organisations. Service providers in remote and rural areas have to be all things to all people, they feel isolated and lack peer support and backup. The more remote the worker, the more likely that s/he will be required to manage a diverse case load. Specialists have been reluctant to establish themselves in rural settings (Fanning, 1993). McKenzie (1992) notes that a strong growth in service industry professions, combined with introduction of standards have resulted in a denigration of nonprofessional staff and an associated reduction in their numbers, even where professional staff are not available. In addition, features of rural employment such as lack of peer support, gender role conflict, blurring of roles, lack of close proximity to other service providers and unrealistic expectations

often result in stress, burnout, high staff turnover rates and lack of continuity between workers. Many professionals return to the city as soon as they are able to obtain a position. According to Fanning (1993), burn-out is common in remote and rural areas. Strategies are presented which are designed to enhance attractiveness of employment in remote and rural areas to attract and retain high quality staff. These strategies are designed to enhance career opportunities, provide status and financial incentives and improve the quality of work life.

Disability awareness education. Evidence from a wide range of sources suggests an urgent need for disability awareness education for service providers and for members of the wider community. Attitudes and beliefs act as major barriers to implementation of recent legislation. It was reported during consultations that many personnel in generic services were not willing to work with people with disabilities and considerable fear still existed within the community about issues associated with disability. Many people seem to believe that it is not their responsibility and that they are not trained to attend to clients with disabilities. Furthermore, many workers come to an area with inappropriate values and attempt to impose these on to others. These attitudes and values were acquired during education and city practice and often do not apply in remote locations. It was also reported that medical staff were often ignorant about disabilities, resulting in major problems with diagnosis and in accessing services. Doctors and other medical professionals often do not have up-to-date information. There were many claims of lack of skills in identifying symptoms, especially for intellectual disability. This lack hindered commencement of early intervention programs for clients. It was also reported that many doctors and medical professionals did not know what disability services were available in their local areas. As medical personnel are often the first and only contact a person has with the health system, they must take the responsibility to refer clients to appropriate services.

"I don't think Home Care workers are trained to work with people who are severely disabled. They often won't service these people. I've felt guilty about requesting a service because I was told that someone else (an old person) was missing out on their shower so my adult child could receive a service." (Parent, Dubbo)

The community's awareness of issues associated with disability was frequently raised as a concern. Parents and carers believed the general public was not aware of issues and was not taught about people with disabilities nor about the nature and scope of disabilities. Many country centres have been the base for 'cradle to grave' institutions which have taken responsibility for the care of people with disabilities. As a result, people with disabilities in many country communities have been segregated from the rest of the population and there has been little opportunity for people with and without disability to get to know each other or to break down negative attitudes and myths about disability. High levels of fear and discomfort still exist in most areas, as does prejudice and discrimination. Wide acceptance exists in many places for old models of service provision which are no longer regarded as appropriate elsewhere and which recent legislation is designed to change.

Information about services and professional education. Many people with disabilities and service providers report difficulty in obtaining up-to-date information. Consumers commented that some service providers seemed poorly informed about disability issues. Strategies are proposed to provide up-to-date information for personnel working in remote and rural areas and for preparing professionals during preregistration education for working in remote and rural areas. One proposed strategy involves extending computer networks and disability data bases. This technology also could be used by people with disabilities.

Computer networks and communications technology. Australia has a history of using technology to overcome the tyranny of distance. Strategies are suggested which build on existing technology and services to address issues such as isolation, difficulty in networking between people with disabilities and service providers and difficulty in obtaining access to up-to-date information.

The above themes over-ride all others impinging on service needs associated with: access to community life and its resources; protection of rights; carers and respite care; accommodation; employment, education; loneliness; politicising of issues; and availability of aids, equipment and appliances.

Particular attention was given in the project to three groups of people who experience double disadvantage: people with disabilities who are women, of non English-speaking backgrounds and are of Aboriginal and Torres Strait Island backgrounds. The study recognised the special needs and interests of these groups, whilst acknowledging individuality and the wide range of diversity within each group.

Women Cooper (1993) argues that women with disabilities are not well protected through legislation in Australia. She argues that the Affirmative Action Act (1986), Sex Discrimination Act (SDA) (1984) and the Disability Discrimination Act (DDA) (1992) have many loopholes and exemptions which weaken their potency. The Australian Bureau of Statistics (1988) revealed that women with disabilities are more often institutionalised, less likely to work for money, less likely to own a house, and less likely to receive requested personal care and household assistance than equivalent males (Cooper, 1993). Issues for women with disabilities include isolation, low self esteem, reduced employment and other opportunities. These issues are compounded in remote and rural areas where only two options may be available for long-term care: family or institution. This situation places considerable pressure on the family to assume the role of primary care giver, despite the impact on lifestyle that this role imposes. Innovative programs are required which are creative and flexible in filling service gaps and which address issues associated with isolation, limited availability of service providers and supports. The whole family should be considered in design of rehabilitation and therapy programs. However, especially in the country it is a fact of life that women are responsible for most of the caregiving. Therefore, special consideration is required to the needs of these women who, particularly in remote areas have caring responsibilities which are over and above an already demanding daily routine.

"I have an adult daughter who has severe brain injury and is extremely disabled. She is partially mobile and I have to care for all her needs. There are no services for her. What will happen to her when I die? (Parent, Dubbo)

People of non English-speaking backgrounds. To date, these people have largely been neglected in regard to policy for service provision in remote and rural areas. Human Rights Commissioner, Irene Moss (1993) noted that a Census of Disability Services undertaken in 1992 revealed that people of non English-speaking backgrounds were under-represented as users of mainstream services available for all people with disabilities (including vocational therapy, diversional therapy, training centres, nursing homes, residential and holiday accommodation, rehabilitation services and recreational centres). They experience difficulties in accessing services and in communicating with service providers. Such difficulties are compounded by having a disability (Ariotti, 1990). The sparse density of populations of NESB people outside major areas suggests that different models of service provision are appropriate. Attention should also be given to members of the deaf community who speak AUSLAN as well as hearing people who speak other than English as the preferred language at home.

People of Aboriginal and Torres Strait Island backgrounds. Very little reference material is available about the numbers of Aboriginal people with disabilities (McDougall, 1993). Results published to date from the 1988 Survey of Disability and Ageing conducted by the Australian Bureau of Statistics do not include Aboriginality. This information from the 1993 Survey of Disability, Ageing and Carers is not yet published. Most information is gathered by word of mouth by health care workers (Bostock, 1991). Thus, trying to determine the number of Aboriginal people with disabilities is impossible given the current level of information. However, a number of factors suggest that the Aboriginal population has a large percentage of people with substantial disability. Aboriginal populations experience a range of acute and chronic diseases not generally seen in other Australian populations (Rose, 1993). These reflect the geographic, occupational, social and economic contexts

in which people live. Service provision for Aboriginal people has become a highly political and visible issue over the last few years. A great deal has been said about Aboriginal social and health status indicators and about the inadequacy of service provision for these people. Government organisations are beginning to develop policy and to implement strategies for addressing the severe disadvantage resulting from culturally-inappropriate services which have existed for many years. However, evidence emerging from this project indicates that few policy makers or service providers have fully come to grips with issues associated with effective service provision for Aboriginal people with disabilities (Tipper & Dovey, 1991). Issues in this area are highly complex and suggest that, if effective services are to be achieved, service providers must step aside from their long-held practices and orientations to take an open and innovative approach to planning and implementation (Eckermann et al, 1992).

Recent legislation demands marked changes in service provision for people with disabilities. Such legislation has provided the contextual framework for this document. Many of the strategies developed in this project will benefit people with disabilities in general, but it is essential that features of living in a remote or rural area are taken into account in planning and implementing new services. The issues emerging from this project are highly complex and multi-dimensional. They do not readily lend themselves to simple solutions or to a step-by-step strategy for addressing needs.

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